

PSJ3

Exhibit 48B



November 7, 2003

American Pain Foundation

201 N. Charles Street, Suite 710
Baltimore, MD 21201
Phone: 410-783-7292
Fax: 410-385-1832
www.painfoundation.org

Ms. Stacey Beckhardt
Sr. Manager
Cephalon, Inc.
145 Brandywine Parkway
West Chester, PA 19380

Dear Stacey:

Thank you for participating in the American Pain Foundation's first Corporate Roundtable meeting. We appreciated the opportunity to present information about our on-going programs and plans for the new initiatives we will be implementing in 2004. We also appreciated the opportunity to hear about industry needs and perceptions about the pain management landscape. I am sorry that we did not have enough time to complete our discussion about your needs in relation to the programs and activities of APF. We do see this meeting, however, as just the beginning—the first step in a long relationship—and hope to continue this dialogue with you and other Roundtable members throughout the year.

As promised, we have reviewed and analyzed the statements that were produced and posted at the end of the day as a means of completing the task of understanding industry's priorities. We have also **listened** to the messages within these postings and the spoken messages of that day. As I mentioned during the morning's presentation, we are in the process of **Listening**—gathering information, perspectives, and needs—from consumers and stakeholders in order to identify our priorities for the coming years.

Attached is a chart displaying our categorization of the priorities we heard in the afternoon discussion. We took the liberty of grouping and naming the categories (something we intended to do at the RT meeting) as we understood them. This process produced a list of six priorities:

- Improving professional education
- Improving public and political understanding and awareness of pain management
- Improving balance in regulatory policy
- Conducting epidemiological research
- Improving access to comprehensive pain management
- Improving collaboration among pain organizations

An independent nonprofit organization serving people with pain through information, education and advocacy

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A brief reflection on APF's Programs reveals that we are doing work in each of those priorities. Some examples include:

- Our **Information and Support Services Program** is publishing the *TARGET Pain* pocket card, intended to educate healthcare professionals about ways to communicate with their patients about pain. There is also a companion piece for patients, the *Pain Notebook*, which includes both a pain diary and tips for communicating with doctors about their pain.
- Our **Advocacy Program** and our **Communication and Outreach Program** engage in several efforts to improve understanding of pain issues within public (i.e., the *Power Over Pain Campaign*) and political arenas.
- Our **Advocacy Program** works at State and Federal levels to improve regulatory policy to create better access to quality care.
- Our forthcoming **National Pain Survey** will produce the kinds of epidemiological information to propel the entire field—policy, research, practice and advocacy—into the next decade of improved pain medicine.
- All of our programs work to improve access to comprehensive pain management whether it is patient education and advocacy, or advocacy for removal of practice or policy barriers.
- Throughout all of our work, we are committed to working collaboratively with other organizations to improve the quality of life for people affected by pain. We also have committed to simplifying the field by pursuing more joint efforts and more joint requests for support.

We would like to follow-up with you about priorities particular to your company—defining the issues and identifying how our work does or can address your priorities. We need more education, for example, about the nature of the reimbursement issues and suggestions for ways that a consumer organization can work to remove those barriers to the delivery of good and comprehensive pain management. We also want to clarify the ways you can support our work.

Our next step will be a contact call from Lennie Duensing to talk with you about specific ways we can work together to improve pain management and get people with pain the relief they need and deserve.

Again, we greatly appreciate your participation in the Roundtable and want to keep the dialogue going. We look forward to our continued collaboration.

Sincerely,



Will Rowe

Industry Priorities

From The American Pain Foundation's
Corporate Roundtable

October 20, 2003

<p>Improve Professional Education in Pain Mgt.</p> <p>Develop common term for pain</p> <p>Educate regulatory/pain bodies about value of pain treatments (CMS, DEA, FDA, etc.)</p> <p>Education of physicians around pain as a diagnosis</p> <p>Evidence based treatment guidelines (& HEDIS guidelines)</p> <p>Hesitancy to Rx, reimburse & take appropriate doses of powerful medications</p> <p>Professional education</p>	<p>Improve Public & Political Awareness of Pain Mgt.</p> <p>Put pain on the political map (i.e. cancer, HIV, depression)</p> <p>Put pain on the popular map (i.e. media, general public, etc.)</p> <p>Defend long-acting opioids</p>	<p>Balanced Regulatory Policy</p> <p>Defend long-acting opioids</p> <p>Funding needs balance:</p> <ul style="list-style-type: none"> -Regulatory -Media -Public ed. -Prof. ed. 	<p>Epidemiology</p> <p>Evidence based treatment guidelines & HEDIS guidelines</p> <p>Drug development & research within a narrow range of diseases</p> <p>Need: epidemiology</p> <p>Innovation is currently stymied</p> <p>Better regulatory input</p>	<p>Improve Access</p> <p>Access to branded pharmaceuticals</p> <p>Reimbursement for comprehensive pain care</p> <p>Changes in healthcare system: -reimbursement -managed care</p>	<p>Improve Collaboration With Pain Orgs.</p> <p>Address fragmentation in pain societies</p> <p>Industry wants to help all associations and advocates but cannot support all--how to help?</p> <p>Collaboration around: specialties specialty orgs. patient/consumer orgs.</p> <p>Funding</p>
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October 20, 2003

American Pain Foundation

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Baltimore, MD 21201

Phone: 410-783-7292

Fax: 410-385-1832

www.painfoundation.org

Dear Roundtable Participant:

We are very pleased that your company has become part of the American Pain Foundation Corporate Roundtable and that you are participating in the first annual meeting of this group. This meeting will provide an opportunity for you to join us in exploring ways we can work together to improve pain management and help people with pain get the care they need.

APF now has six year's experience in providing education, information and support for people affected by pain, increasing public awareness, and promoting better pain law and policy. As we move into 2004, we want to share our vision and plans with you. From you, we want to learn about trends and challenges from an industry perspective. And, we want to use these discussions to identify ways we can partner on mutually beneficial projects and programs.

Know that we've been taking stock and looking at ourselves frankly. We've been listening to the people we serve and assessing how well we're serving them, and we're looking at how APF fits into the pain management landscape. Although we continue to get overwhelmingly positive responses from our constituents, we also know that there is far more we need to do to meet their needs and our mission. We are ready and prepared to take bold steps to do what needs to be done.

For example, at the Roundtable meeting you will hear about our plans for:

- Mobilizing individuals across the nation, particularly those affected by pain, by bringing them onto the public stage and giving them the tools and support they need to make their voices heard.
- Expanding ***Power Over Pain***, an action-oriented public awareness campaign APF is successfully piloting in Florida, Louisiana, and Massachusetts in collaboration with the American Alliance of Cancer Pain Initiatives.
- Creating a new initiative that will provide personal, one-on-one, support and advocacy for people with pain and caregivers who are desperately trying to get help, yet are having difficulty getting the care they need.
- Conducting the first-ever scientific study of pain in the United States—a study that will provide us with the information we need to inform and guide our work, and demonstrate the need for better legislation and research.
- Expanding and enriching our existing services and programs to include information, resources, and support for caregivers (with an emphasis on those caring for children and people at the end of life) and undeserved populations.

We are invigorated by the challenges facing us and optimistic that you will want to partner with us in these endeavors.

Sincerely,

Will Rowe
Executive Director

An independent nonprofit organization serving people with pain through information, education and advocacy

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Missions & Values

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American Pain Foundation

Mission Statement

The American Pain Foundation is an independent, nonprofit organization serving people with pain through information, education and advocacy. Our mission is to improve the quality of life for people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management.

American Pain Foundation Corporate Roundtable

Mission

The Mission of the Corporate Roundtable is to foster and deepen relationships between the American Pain Foundation and members of industry for the purpose of achieving our mutual goals—to improve pain management and better the lives of people affected by pain.

THE CORE VALUES OF THE AMERICAN PAIN FOUNDATION

We, at the American Pain Foundation, are committed to fundamental values that govern our thinking and work.

WE VALUE CARING AND COMPASSION. We recognize that the most fundamental reason for our work is that we care about people. Our organization is here to make a difference in the lives of people affected by pain, because we care. We care about the individuals we serve, we care about each person on our team, and we work toward our mission in a caring and compassionate manner.

WE VALUE KNOWLEDGE. We know that the most effective way to serve people affected by pain is by applying the most current knowledge available. We are committed to *best practice* in both the pain management field and in the operation of our business.

WE VALUE INTEGRITY. We are committed to building trusting relationships with those we serve, those who support us, other organizations, and among ourselves. We recognize that this requires speaking and behaving openly and honestly in all areas of our work, and never acting in ways contrary to our mission. We are committed to doing what we intend and promise.

WE VALUE DIVERSITY. We know that the best way to reach and serve people affected by pain is to *live the value of diversity*. Best knowledge and best caring can only be accomplished with inclusiveness, openness, and cultural competence. We approach our work with an unswerving commitment to eradicating the prejudice, discrimination, and inequities that pervade our medical system and prevent people from getting the pain care they need.

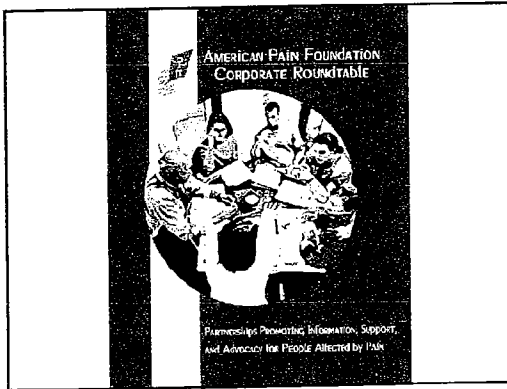
WE VALUE TEAM WORK AND COLLABORATION. We understand that the enormous challenges of fulfilling our mission can only be accomplished by the work of many. We are committed to working collaboratively with each other, with our constituents, and with other organizations committed to the goal of improving pain management and helping people affected by pain get the care they need.


WE VALUE LISTENING TO PEOPLE AFFECTED BY PAIN.

Because people with pain are the experts on pain, we are committed to listening carefully to what they say about their experiences and needs, and we use that information to guide, inform, and grow our work.

WE VALUE CREATIVITY AND OPENNESS TO NEW IDEAS. We recognize that we are only at the beginning of our work and just learning how to better serve those affected by pain. We are committed to approaching our work creatively and boldly, with openness to new ideas, and without preconceived notions about how things should be done.

WE VALUE JOY, HUMOR, AND ENTHUSIASM. We recognize that the spirit in which we do our work is vital to the work itself. We know that joy, humor, and enthusiasm, keep our spirits lively through the difficult work we do. We encourage joy and humor in the workplace and sharing that joy with the people we serve.





Our Story Begins...

With approximately 75 million Americans—men, women, and children—who live with serious chronic pain that affects almost every aspect of their lives.



**Here's what
they say...**

The Shame! The Outrage!

- The medical knowledge is available to eliminate or reduce most pain problems.
- Yet most pain goes untreated, under-treated, or improperly treated.

The Shame! The Outrage!

**Pain has not gotten the attention it
deserves from:**

- Healthcare organizations
- Research institutions
- Policy makers
- The Media
- The Public



Our Story

- APF was founded in 1997 by three past presidents of APS.
- APF is the nation's largest organization serving consumers affected by pain

Our Mission

To improve the quality of life for people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management.



Our Core Values

We Value:

- Caring
- Knowledge
- Listening to People Affected by Pain
- Integrity
- Diversity
- Teamwork & Collaboration
- Creativity & Openness to New Ideas
- Joy, Humor, and Enthusiasm

Who We Serve

- People with Pain
- Caregivers, family members and friends of people with pain
- Healthcare professionals who provide care for people with pain.

At APF, It's NOT Just Business—It's Personal!

**The work of APF is about the people
- the INDIVIDUALS-
we serve.**

It's Not Just Business— It's Personal

- Increasingly, our work grows out of the needs and requests of people with pain and their caregivers.
- Today, more and more people affected by pain are joining us.
- They are speaking out and reaching out to others affected by pain, policy makers, and the media.

How We Work

- **LISTEN**—Working closely with people affected by pain, we listen to their stories to understand their needs.
- **TARGET**—In response, we develop clear goals and targets for our work.
- **GET RESULTS**—We are committed to results that improve the lives of people affected by pain.

How We Work Together

We work collaboratively with others to achieve the best results:

- People affected by pain
- Organizations and businesses dedicated to helping people with pain
- Government and regulatory agencies

We Provide Information

Thousands of people reach us through our:

- **Toll-free Info Line:** 1-888-615-PAIN
 - Consumers can request printed materials on range of pain-specific issues
- **Email Info Line:** info@painfoundation.org
 - Consumers submit questions and receive information



We Provide Information

Free publications to help those in pain find the care and learn how to advocate for themselves.

- Distributed to over 1 million individuals and healthcare institutions in 2002.
- Helped ICAHO facilities meet required pain standards.

Finding Help for Your Pain

Reading This Could Help Ease Your Pain


Companion Publications Coming Soon

- **TARGET PAIN**—a pocket card for healthcare professionals as a reminder to ask patients about their pain, assess their pain, ask about persistent and breakthrough pain.
- **PAIN NOTEBOOK**—a pain “diary” for consumers and tips for communicating with health professionals.

We Provide Information

The Pain Community

The Newsletter of the American Pain Foundation



Pain Headlines



We Provide Information

The Pain Community News

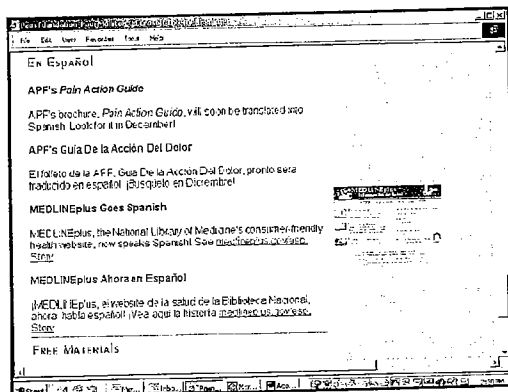
- Published 3 times a year
- Each issue focuses on a timely topic
- Includes pain news, interviews, resources, complementary and alternative information

We Provide Information

Free monthly E-newsletter: *APF Pain Monitor*

- Easy-to-read info including:

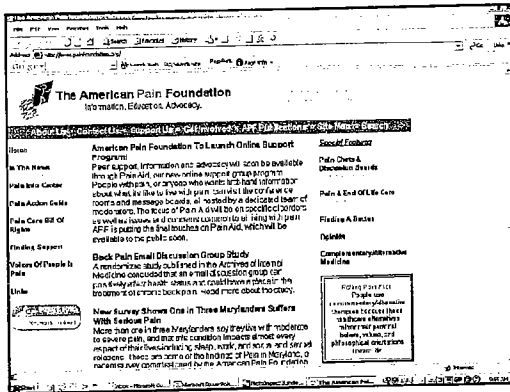
- Website-of-the-month
- Free resources
- Spanish language items
- Pain News
- Science & medicine



We Offer Support

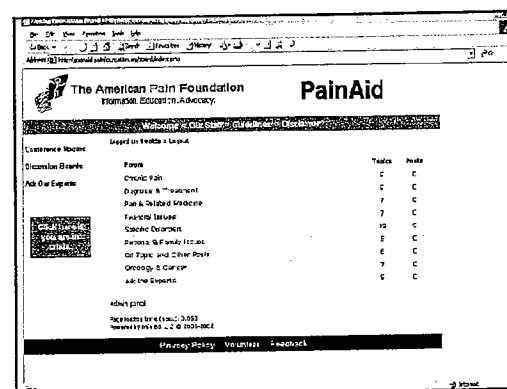
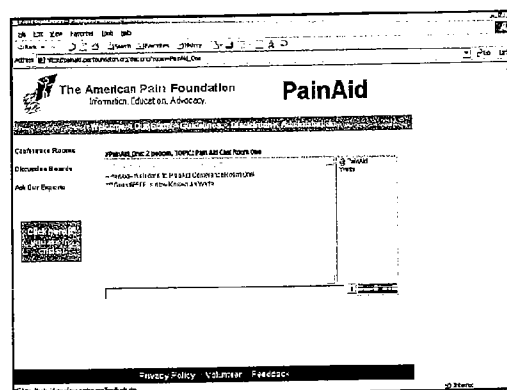
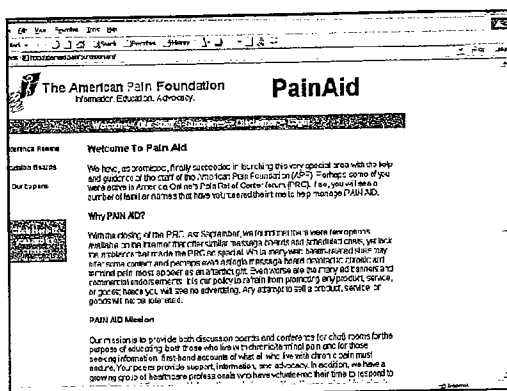
Online Consumer Services

- **APF Website**
<http://www.painfoundation.org>
- **PainAid: Online Support Program**
<http://painaid.painfoundation.org>
- **Technology-Based Projects**



PainAid: Online Community

- **90 message boards on range of issues:**
 - Psychosocial challenges
 - Conventional and CAM treatments
 - Opioids and other medications
 - Financial/insurance/disability & much more
- **Live chats with guest speakers and experts**
- **Ask-the-Expert service w/ 10 licensed professionals**



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PainAid User Response

"...I have waited a long time for this site to open. Thanks for everyone's hard work. I've had chronic pain since 1991...It hasn't been easy to get the kind of care I needed and many times I wanted to give up. I was able to keep going because of the information and support I received in online message boards. My message to others is don't give up or give in to poor pain control."

PainAid User Response

"I don't plan on spending lots of time here because I have a life to live and sitting at my computer for many hours is not living for me anymore. This is the result of good pain control. I didn't start out this way...I hope this message gives hope to others still trying to find good pain management."

PainAid User Response

"It really is great knowing our old family has a new home :-). If you're new here, stick around because you're in for a real treat! These are some of the most caring, sharing, or "just have fun & forget about your pain for a while" people anywhere on the 'Net!'"

Next Steps

- Reorganization of APF Website
- Special attention to underserved people with pain
- Pain & End-of-Life Section
 - Articles, info, resources
 - Facilitated online discussion forum

Next Steps

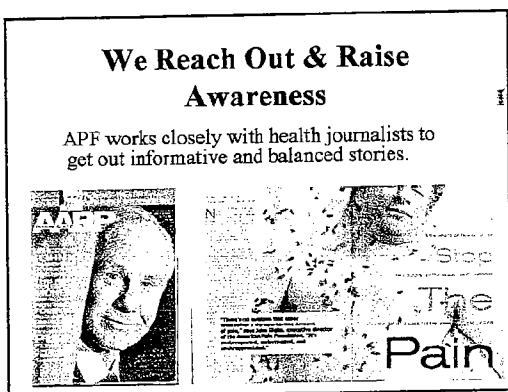
Personal Advocacy - Train personal pain advocates around the nation who will provide personal support/navigation for people with pain who are facing obstacles in achieving access to appropriate pain care.

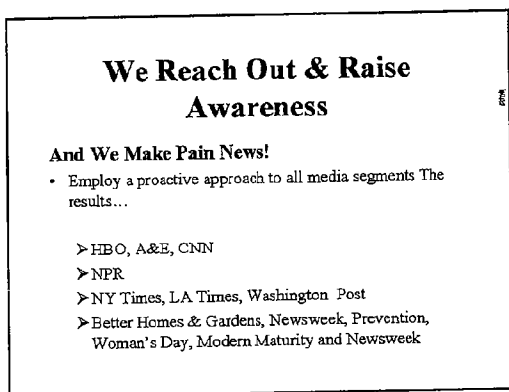
- Personal Advocacy training
- Outreach to individuals
- Online searchable resource database

Next Steps

• Focus on Children and Youth

- Info/resources for children and adolescents with pain
- Info/support for parents of children and adolescents with pain









We Reach Out & Raise Awareness

Power Over Pain Campaign

- A collaborative project with AACPI
- Participation by ACS and ASPMN
- Grassroots : State/local level
- Goal: To increase awareness of pain management issues among public, healthcare professionals, policy makers, and media.



We Reach Out & Raise Awareness

- Piloting project in 3 states: Florida, Louisiana, and Massachusetts.
- Led by Pain Initiatives working with regional divisions of the American Cancer Society.
- Conducted statewide surveys that gained wide media attention.

Next Steps

Community Advocacy

- Develop and train a cadre of community advocates around the USA to:
 - "Hit the streets" with pain management information.
 - Drive consumer demand for better pain care.

We Advocate For “Best Practice” Pain Legislation & Public Policy

Raise legislative awareness about pain issues that:

- Promote professional education
- Reduce regulatory barriers to accessing pain care
- Increase federal funding for pain research
- Expand coverage for pain treatments and medications
- Require pain assessment/treatment in federally-funded programs

Next Steps

Issues Advocacy

- **Implement Mobilization Strategies** to harness and direct thousands of voices around critical issues that affect people with pain e.g., laws, policies, media and public events
- **Establish an online action center**

National Pain Survey

APF in collaboration with MD Anderson Cancer Center, at the University of Texas, will conduct the first epidemiological survey of pain in the US.

National Pain Survey

The Study will measure the:

- Extent and magnitude of pain in the US
- Impact
- Causes of pain
- Effectiveness of treatment
- More

National Pain Survey

Need for Survey:

- Industry, healthcare professionals, and patient advocacy groups have no definitive data to guide and inform their work.

National Pain Survey

- Without knowledge of magnitude of pain and its consequences, federal agencies cannot establish effective national policies on pain, pain research, pain treatment, and funding.

National Pain Survey

Methodology:

- 10,000 person sample size
- Random digit dialing
- 20-30 minute interviews

Agenda

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**American Pain Foundation
Corporate Roundtable Meeting**

The Walters Art Museum
Baltimore, Maryland

Monday, October 19, 2003

AGENDA

10:00-10:25

Welcome and Opening Remarks

James N. Campbell, MD, Professor of Neurosurgery
Director, Blaustein Pain Treatment Center
Johns Hopkins University Medical Center
Chair & President, APF Board

New Directions

Will Rowe, Executive Director

Story

Laura Simms, Master Storyteller

10:25-12:10

American Pain Foundation Program Overview

Will Rowe, Yvette Colón, Micke Brown, Lennie Duensing,
Carol Harper

12:10-12:30

National Pain Survey

Bill Frey, PhD
Associate Director in Health Studies, Westat

12:30

Lunch Buffet /Break

12:45-1:00

Guest Speaker

Adrienne Braun, Community Advocate & Caregiver

1:00-1:15

Trends and Barriers

Russell Portenoy, MD, Chair
Department of Medicine & Palliative Care
Beth Israel Medical Center

1:15-2:00

**Trends and Issues in Pain Management
Industry Perspective (Discussion)**

2:00-3:00

Partnership Opportunities (Discussion)

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Projects/Partnership
Opportunities

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American Pain Foundation
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The American Pain Foundation An Overview

Introduction

The American Pain Foundation (APF) is the nation's largest and most active nonprofit organization devoted exclusively to serving the needs of people with pain through information, advocacy, and support. Our mission is to improve the quality of life for people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management.

APF was founded in 1997 by three of the nation's leaders in pain management:

- Dr. James Campbell, Director, Blaustein Pain Treatment Center, Johns Hopkins Hospital
- Dr. Kathleen Foley, Pain & Palliative Care Services, Memorial Sloan Kettering
- John Liebeskind, Ph.D.

They recognized that while a few professional societies existed for physicians, nurses, and other professionals specializing in pain management, there was no national nonprofit organization dedicated entirely to serving and representing pain patients. Today, with a staff of fourteen people and a solid funding base, APF is the leading organization serving people affected by pain.

Free Services that APF Provides to People with Pain

In 2002 APF helped over 1 million people with pain, their families, and caregivers through a variety of free services:

- **Publications.** Our free *Pain Action Guide*, *Finding Help for Your Pain*, and *Pain Care Bill of Rights* (in English and Spanish) provide pain patients with practical information for getting the care they need, tips for talking to their doctor or nurse, common myths about pain, and how and where to find help. These and other publications have been distributed to more than a million patients nationwide, and the demand is growing. Coming soon: our Pain Care Bill of Rights in Chinese, and companion publications focusing on managing pain and communications for healthcare professionals and people with pain.
- **Comprehensive Consumer-Focused Website (www.painfoundation.org).** Millions of people with pain are now going to the Internet for help. Some of the

information is not medically sound and most good information is highly technical. Our easy-to-use website was designed for lay persons. In 2002, site visits tripled to over 45,000/month. The site includes:

- Up-to-date, reliable information about pain and treatment options
 - How to find help
 - News stories and background information
 - Links to over 200 carefully-selected websites, and more
- ***PainAid***. Launched last year, *PainAid* is the interactive component of APF's website. This online community is designed for and shared by those who live with chronic and terminal pain. Through moderated message boards, chat rooms and Ask-The-Expert discussions, participants share information and experiences in an organized, supported, and quality-controlled environment, and learn skills needed to improve their lives.
 - **Toll-free Consumer Information Line (1-888-615-PAIN)**. For people without access to the Internet, APF is one of the few nonprofit organizations consumers can call free of charge. We provide them with a variety of targeted fact sheets and basic information. In 2002, we responded to over 3,200 calls on our toll-free line.
 - **Consumer Email Information Service (info@painfoundation.org)**. Consumers who have a hard time finding information on the Internet can simply email their questions to us. Each month we set a new record for requests and expect this growth to continue.
 - ***The Pain Community News***. Each issue of our newsletter focuses on a critical problem in pain care, showcases other organizations serving people with pain, and provides legislative updates and resources for getting help. Circulation continues to grow and we currently communicate with 60,000 individuals and organizations nationwide.
 - ***The Pain Monitor— Monthly Consumer E-Newsletter***. Our monthly electronic publication focuses on news and information of use and interest to people affected by pain. It also provides clinical content on the latest in medical news. *The Pain Monitor* was launched the first week of January 2003 to very positive reviews. We continue to receive feedback from people with pain indicating that the e-newsletter has helped them better explain their situations to people in their lives, find resources, realize there is a support community available to them, and find the information they need. The professional community has been very impressed with the content as well.

How APF Raises Public Awareness and Reaches Out

- ***Power Over Pain, a Grassroots Public Awareness Project***. In collaboration with the American Alliance of Cancer Pain Initiatives (AACPI), and with the support of divisions of the American Cancer Society and the American Society of Pain Management Nurses, APF has launched an action-oriented, grassroots public

awareness campaign in Florida, Louisiana, and Massachusetts. Led by Pain Initiatives in each state, activities include:

- Educating the public about pain care through local media activities and community education programs
- Conducting workshops and distributing our educational materials to patients through hospitals, doctors' offices, community centers, and places of worship
- Establishing Pain Awareness Month as a way to draw public and media attention to the pain problem

The campaign was launched with statewide surveys that received wide media attention.

- **Power Over Pain Community Action Kit.** APF has written a comprehensive how-to guide that includes information on forming coalitions and organizing the community, specific "action" ideas, a media kit, and resources. The *Community Action Kit* is available to anyone wishing to conduct the Campaign in their area.
- **We Get the Message Out About the Pain Problem Through the Media.** We change attitudes about pain and break down barriers to better care, by informing the public, healthcare professionals and opinion makers about how vast the pain problem is and ways to tackle it. APF is the only organization of its kind with a full-time Director of Communications and Outreach. Our organization and messages have been featured or discussed on CNN, CBS News, ABC News, HBO, A&E Network, Good Morning America, *USA Today*, *Wall Street Journal*, *New York Times*, *LA Times*, *Baltimore Sun*, *Boston Globe*, *Chicago Tribune*, National Public Radio, *U.S. News and World Report*, *Better Homes and Gardens*, and *Prevention Magazine*, *AARP*, *GQ*, *Prevention Magazine*, *Modern Maturity*, among others.

We Fight in Washington for Better Laws and Policies to Improve Pain Care

APF is the only consumer organization with an advocate based in Washington, D.C. Three years ago APF formed and led the first-ever *Coalition to Improve Pain Management*, which brought together over 60 patient, healthcare, and medical organizations to defeat a federal bill that would have restricted access to powerful pain medications. We are now leading an effort to introduce and pass comprehensive federal legislation to improve pain management nationwide.

Where APF is Heading: Critical New Projects to Help People with Pain

Over the next 12 months, the American Pain Foundation plans to launch several major, well-defined projects to benefit people with pain:

- **Conduct a Nationwide Survey on Pain.** In collaboration with Charles Cleeland, Ph.D., Director of the MD Anderson Cancer Center Pain Research Group, planning for the first truly independent, comprehensive national survey has begun. The

survey will focus on the extent and impact of pain in the United States, including current treatments being used, and the barriers and problems to getting effective relief. The data gathered will be used for scholarly research and to educate the media, the public, and opinion makers on the breadth of this problem and the need to address it.

- **Create a Consumer Mobilization Strategy** to direct thousands of consumer voices at particular public issues, state and federal legislative and policy issues. We will be mobilizing consumers to direct phone calls, letters, and visits to particular targets of influence to stimulate improvement in public understanding, and public law and policy.
- **Increase Distribution of Patient Education Materials and Translate Materials into Spanish.** Demand continues to grow for our educational materials. We are planning to translate all of our patient education materials into Spanish.

10/2003

Information/Education

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PAIN CARE BILL OF RIGHTS

As a person with pain, you have the right to:

- have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists, and other healthcare professionals.
- have your pain thoroughly assessed and promptly treated.
- be informed by your healthcare provider about what may be causing your pain, possible treatments, and the benefits, risks, and costs of each.
- participate actively in decisions about how to manage your pain.
- have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.
- be referred to a pain specialist if your pain persists.
- get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.

Although not always required by law, these are the rights you should expect for your pain care.



DECLARACIÓN DE DERECHOS PARA TRATAMIENTO DE DOLOR

Como persona con dolor, usted tiene el derecho de tener su informe de dolor tratado en serio y con dignidad y respeto por doctores, enfermeras, farmacéuticos y otros profesionales en trato de salud.

□

el derecho de tener su dolor completamente considerado y tratado en seguida.

□

el derecho de ser informado por su doctor acerca de la causa mas probable de su dolor, tratamientos posibles, y los beneficios, los riesgos, y el costo de cada uno.

□

el derecho de participar activamente en decisiones acerca de la manera de controlar su dolor.

□

el derecho de tener su dolor evaluado de nuevo regularmente y su tratamiento cambiado si su dolor no se ha disminuido.

□

el derecho de ser referido a un especialista en tratamiento de dolor si continua su dolor.

□

el derecho de recibir respuestas claras e inmediatas a sus preguntas, de tener tiempo para hacer sus decisiones, y de rehusar cierto tipo de tratamiento si usted desea.

□

Aunque no siempre exigidos por la ley, estos son derechos que deben ser esperados, y si necesario, exigirlos para tratamiento de su dolor.

疼痛病人的權利書

如果您身受疼痛，您享有以下的權利：

當您告訴您的醫生，護士和醫務人員您有疼痛時，您有權利得到他們認真的處理及以尊重您的方式給予治療。

當您有疼痛時，您有權利得到徹底的評量和即時處理。

您的醫生有義務告知您引起疼痛的可能原因及各種有效的治療方式和治療方式的利弊，風險度和費用。

您有權利積極的參與及決定您的一切疼痛治療方式。

您的疼痛可得到定期的評量，如果您的疼痛沒有得到減輕，您有權利要求調整疼痛治療方式。

如果您的疼痛繼續，您有權利轉診到疼痛科專家。

如果您有問題，您有權利得到清楚和迅速的答案；並且您有權利獲得充裕的時間做決定及選擇拒絕某種治療方式。

*Canlonesse Translation from Cabrini Center for Nursing and Rehabilitation Pain Relief Team 12/02
Adapted from Pain Care Bill of Rights: The American Pain Foundation
201 N. Charles Street, Suite 710
Baltimore, MD 21201-4111*

Communications

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AMERICAN PAIN FOUNDATION

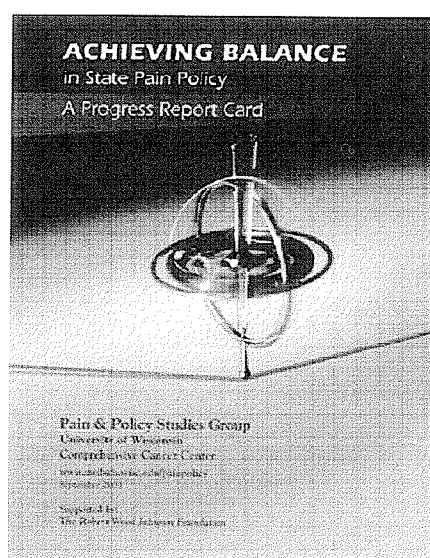
INFORMATION ADVOCACY SUPPORT

APF PAIN MONITOR E-NEWS FOR THE PAIN COMMUNITY

THE NEWS

PPSG Releases Progress Report Card
The Pain & Policy Studies Group at the University of Wisconsin today released its *Progress Report Card (PRC)*, a product of the ongoing pain and public policy research program. The PRC grades and ranks states based on a recently updated evaluation and quantification of state pain policies.

The report is accompanied by a companion policy analysis, the second edition of *Achieving Balance in Federal and State Pain Policy: A Guide to Evaluation (2003)*. The work is supported by the Robert Wood Johnson Foundation. For more information and to view both documents, the national press release, and supplemental information please go to www.medsch.wisc.edu/painpolicy/2003_balance.



Power Over Pain—Join the Campaign!

The American Pain Foundation (APF) and divisions of the American Alliance of Cancer Pain Initiatives (AACPI), with the support of the American Cancer Society and the American Society of Pain Management Nurses, have joined together to implement a grassroots effort called the *Power Over Pain Campaign*. **STORY**

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The BEST OF The Pain Community NEWS

The Newsletter of the American Pain Foundation

Summer 2003



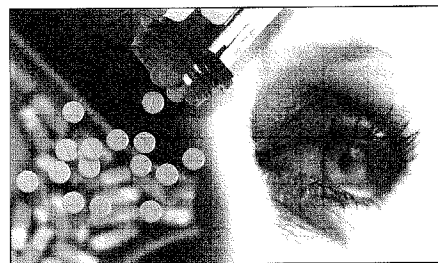
This issue of *The Pain Community News* brings you the articles you asked for and more!

Addiction, Physical Dependence, Tolerance. Confused?

Together, Pain and Addiction Organizations Recommend New Definitions

Addiction, tolerance, and physical dependence—for decades, the three distinct terms have been confused and used interchangeably by the public, healthcare professionals, scientists, and regulators alike. This confusion has had the tragic conse-

quence of leaving many people with severe pain undertreated because they—or their doctors—fear that opioids will cause addiction.



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But last month, the American Academy of Pain Medicine (AAPM), the American Pain Society (APS), and the American Society of Addiction Medicine (ASAM) jointly issued a consensus paper called *Definitions Related to the Use of Opioids for the Treatment of Pain*. This document clearly defines addiction, tolerance, and physical dependence and discusses how each relates to opioid use in the treatment of pain. The importance of the

Addressing Common Concerns

"The three organizations formed a liaison committee in response to the perception that there's an overlap in the pain population—some people with pain have addictive disorders. And there was uncertainty about treatment and diagnosis in these cases," said Edward Covington, MD, Director of the Chronic Pain Rehabilitation Program at the Cleveland Clinic and past president of AAPM, who was one of the paper's authors. "Also, we needed agreement about what is and what is not an addictive disorder."

"The addiction community was concerned because of inaccurate diagnosis. The pain community was concerned about over-diagnosis of addiction when it didn't exist, and how this misdiagnosis interfered with treatment with opioids," Dr. Covington pointed out.

But, how do these definitions of addiction, physical dependence, and tolerance differ from others?

"The definitions of addiction used by the American Psychiatric Association and the World Health Organization (WHO) rely heavily on the concepts of tolerance and withdrawal as indicators of addiction," Dr. Covington said. "We believe this is erroneous. Also, to make matters more confusing, the WHO got away from using the word 'addiction' and they use 'dependence' instead—a term which has an entirely different meaning to us."

Addiction—What It Is

According to the new definition, "Addiction is a primary, chronic, neurobiologic disease, with genetic, psychosocial, and environmental factors..."

"Addiction," Dr. Covington explained, "can be identified by the three 'C's'—craving or compulsive use, loss of control, and use despite adverse consequences, such as divorce, liver disease, or waking up in strange places."

Other behaviors that signal addiction include "drug seek-

ing," taking multiple doses of medications and an inability to take them on schedule, "doctor shopping," and frequent reports of lost or stolen prescriptions. Isolation from friends and family members, taking analgesic medications for sedation or increased energy, or to get "high" are other behaviors that indicate addictive disorder.

Both pain and addiction specialists agree that, in most cases, patients taking opioids do develop physical dependence. Less often they develop tolerance. But they rarely develop an addictive disorder.

Unlike tolerance and physical dependence, addiction is not a predictable effect of a drug, but an adverse reaction in biologically and psychosocially vulnerable individuals.

Addiction—What It's Not

Pseudoadddiction
Often, when patients are undertreated for pain, they will behave "like addicts" to get the relief they need. They will focus on getting medication, appear to be engaging in "drug-

Confusion about these terms has had the tragic consequence of leaving many people with severe pain undertreated.

seeking" behaviors, "clock watch," and even lie to get drugs. But unlike a person with true addictive disorder, once their pain is properly managed, these behaviors stop immediately.

Dr. Ray believes it's important for doctors to recognize the difference between true addiction and pseudoadddiction. "We don't want to frighten practitioners out of giving appropriate opioid treatment when it's indicated—nor do we want to misdiagnose addiction when it's staring us in the face. We want to present something to the medical world on what addiction really is so that it's not confused

(continued on page 8)

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Pain Patient Finds Relief

An Interview With Mary Vargas, Staff Attorney, National Association of the Deaf Law Center, Chronic Pain Sufferer, and Pain Management Activist

At age 23, Mary Vargas had it all—boundless energy, intelligence, and the determination to make positive changes in the world. But shortly after her first year of law school and marriage, Mary was in a car accident that resulted in five years of unrelenting pain. After frustrating experiences with 11 doctors, Mary decided it was time to take action. She became an educated and persistent consumer—and her work paid off.



What would Mary Vargas tell others with pain? "... you have to do a lot of research. Also, you need to be persistent and ask doctors hard questions. When they say you'll never get better—refuse to accept it!"

Q. Mary, tell us a little about yourself—your background?

Vargas: I grew up in New Jersey and went to the College of New Jersey to become a teacher of the deaf. In my third year, I got a Truman Scholarship, which included \$30,000 for graduate school. Before I completed college, I decided to go to law school. Although I loved being in the classroom, I wanted to change education for the deaf from a legal perspective. A week before beginning law school, I married Nelson Vargas. He was working as an attorney for the U.S. Department of Justice.

Q. When did your pain start?

Vargas: I had finished my first

year of law school and was about to start my first legal job. My friend and I were driving to a flower farm. I was waiting to turn into a parking lot when I was rear-ended by a woman who was looking at the scenery. My car propelled forward. Luckily, my friend saw the stone wall we were about to smash into, and I was able to stop in time.

But after the car stopped my head and neck were burning up the left side. Back then, I didn't even have a family doctor, so I went to the ER. The doctor gave me painkillers and muscle relaxants, said I would be better soon, and sent me home. That was on a Friday. By Monday morning, the pain was so unbearable I had to find a doctor right away.

Q. Was that doctor able to identify the problem?

Vargas: No. He told me I had whiplash and that most of these injuries get better in about six months. But, I didn't get better. The pain just kept getting worse and worse. I ended up in his office several times over the next few weeks. Neither he nor I understood what was happening and how big it was going to be. Fortunately, I was working at Yale Law School, where they have a disabilities law clinic—so they could understand my problem.

Q. Were you able to continue going to law school?

Vargas: Yes, but things were getting worse. I often had to leave classes because the pain

in my neck and back of my head would get very bad, and I would get sick to my stomach. This went on for two years. I managed to continue school, but all the fun was out of my life. I couldn't do the things I liked to do. There wasn't time for anything except dealing with pain. My personality went flat.

Q. When did things start turning around?

Vargas: When it looked like nothing was going to work, my husband and I decided to

begin doing some research. I didn't even know that there were pain doctors or anything about pain medications. I had been listening to what the doctors said, and waited and waited. But I knew this wasn't going to go away and that I had to be persistent. Life was beginning to pass me by.

In the summer before my last year of law school, a gifted physical therapist referred me to Dr. Robert Gervin in Bethesda, Maryland. He was the one who really looked at this as a serious problem and began figuring out solutions. He was the first doctor who really got it! When things didn't work he tried something else. He developed a long-term plan and would ask me what was working and what wasn't. He was also the first doctor who really discussed opioid medications with me—what they were, what they would do, and what they would not do. He discussed responsible use and talked openly about addiction issues to alleviate my fears.

Q. How did you feel about taking opioids?

Vargas: I had serious concerns, but at that point I was so miserable I would have done anything to stop the pain. My husband, however, was
(continued on page 8)

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Finding the Help You Need—Is Anybody Out There?

An Interview with Micke Brown, RN, BSN, President, American Society of Pain Management Nurses

Q. What is the first thing a person in pain should know?

Brown: Anyone with serious pain should visit their healthcare professional immediately. Pain lets the body know something is wrong, and may be signaling an underlying disease or infection. Pain should be assessed and addressed. In the last decade, we've learned that pain is a health problem in itself. Untreated pain can be extremely damaging to the body. When pain is managed, the body heals better and faster. Unfortunately, many healthcare professionals don't understand this.

In addition, many people with pain wrongly believe that pain is something they just have to live with—part of their disease or condition, or a natural part of aging. The fact is that most pain can be relieved with proper pain management.

Q. We know that people with pain often find getting help difficult. How do you start?

Brown: Become your own best advocate! Decide that you will manage your pain rather than have your pain manage you. Learn all you can about pain and pain management options. Find a healthcare provider who

knows how to treat pain and will listen carefully to you.

Also, realize that you are the expert on your pain. Learn to communicate your pain symptoms clearly—frequency, intensity, location—so you can contribute to the assessment of your pain. Take an active role and work together to develop a good pain management plan.

Find a trusted co-advocate who will go with you to see your healthcare provider. Your co-advocate can be extremely helpful, particularly at times when your energy is low.

Understand from the outset that this process can be difficult and will take a lot of work and probably a lot of time. But it is well worth the effort.

Q. What would you tell a person with pain who is looking for a healthcare provider?

Brown: Look for a healthcare professional with knowledge about persistent pain who will help you lower your pain to a tolerable level. Most importantly, find a provider who listens carefully, asks questions, and encourages you to ask questions.

Also, have a realistic expectation of relief. Persistent pain tends not to disappear. But your provider must work with

you to bring you back to "living life again."

Q. When should a person with pain seek a pain specialist?

Brown: It's time to find a specialist if your healthcare provider is not successful in treating your pain—if treatments aren't working or your pain worsens. Many people don't know that pain specialists exist!

Ask your current provider whom he or she would go to for a pain evaluation. Ask people who have had their pain treated successfully. Nurses can be good patient advocates. Contact the largest hospital in your area, or a local hospice. Look for state chapters of national pain organizations, such as the American Society of Pain Management Nurses or your state pain initiative.

Check websites to find pain specialists. If you do not have a computer, ask a friend or your local library to perform a search.

Q. Are all pain specialists and pain clinics the same?

Brown: No. Pain specialists can be anesthesiologists, neurosurgeons, psychiatrists,
(continued on page 6)

One of the greatest challenges people with pain face is finding a healthcare provider who knows how to treat pain. Pain management nurse Micke Brown offers this advice:



Micke Brown, RN, BSN

Getting Down To The Truth About Chronic Pain

An Interview with Arthur Rosenfeld, author of the new book, *The Truth About Chronic Pain: Patients and Professionals on How to Face It, Understand It, Overcome It*

Q. Arthur, how did a novelist come to write a book about chronic pain?

Rosenfeld: About fifteen years ago, when I was working as an executive at Purdue Pharma, a well-known pain doctor convinced me that there was a problem in medical education—that doctors had inappropriate prejudices and inaccurate information about the risks of opioids and how and when they should be used. I was sensitive to his argument because my wife was suffering serious pain at home, having been brain damaged and paralyzed in a car accident, and because my uncle, who was very dear to me, was at the NIH dying from cancer. I watched both their trials and wondered why nobody could help them be comfortable, and I found no satisfactory answer.

Q. There are some very good books about pain for consumers. What makes your book different from these? How did you approach the subject?

Rosenfeld: I read many of those books, and they frustrated me. Despite good information, they were written with what was, to me, too great a distance between the subject and the heart, put forth with a

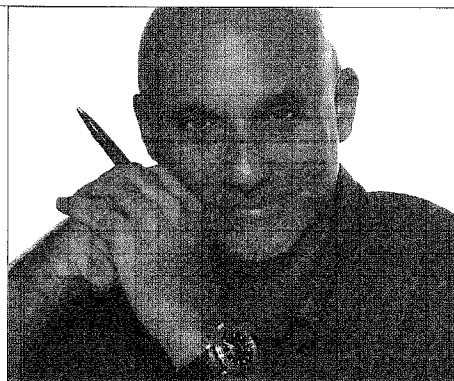
I kept being stunned...by the fact that my belief systems were repeatedly challenged.

journalistic dispassion that I understood from a professional point of view, but which struck me as inappropriate when dealing with the human suffering. I felt that the subject was actually better suited to the novelist, who is by nature trained to look at the underside of things and pick apart what makes people tick.

I wanted to write something small, intimate, and powerful—a call to action. Because I'm neither a scientist nor a doctor, I don't have to fix the human heart, nor do I have to understand how it works. I have to move it, to make it beat faster. I felt that a book that revealed our fears, our confusion, or prejudices and our lack of compassion would be a powerful tool with which to help people in pain.

Q. Your book contains a series of conversations. What made you choose that format?

Rosenfeld: I can't speak with authority about chronic pain because I don't suffer from it



and I don't treat it. So I went to people who know more than I do, a trio of distinct groups, for a three-dimensional view. The first group included a wide range of healthcare professionals, including doctors, a healing touch practitioner, a pharmacist, and a researcher. The chronic pain patient was the second group. I didn't want a catalogue of symptoms or a litany of woes; I wanted to talk to people whose experiences with chronic pain varied, and make them as wide as possible. I was aware that the demographic for chronic pain patients skewed slightly toward women and I wanted neither to indulge nor ignore that. I tried to find people who were articulate about what they were experiencing. I tried to run the gamut as much as one can in this microcosm of experiences that fits between two hard covers.

The third group was the thinkers—people who were involved in medical ethics, philosophers, social commentators, and clerics. I did about forty-eight interviews in all, but ended up chiseling them down in the end. When it came down to choosing people, there was no system I used. But, I was a bit wary of talking to "experts" in these various fields. That included expert chronic

I was especially careful to make sure that no particular points of view were represented other than the prejudice that came from my own head—and that is I believe that people in pain need to be treated.

pain patients as much as chronic pain doctors and expert chronic pain ethicists, because I was afraid of getting canned speeches. I was afraid

of getting a party line. I was afraid of agendas. I was eager to keep these out of the book because it was written with a grant from a pharmaceutical company. I was extra, extra sensitive even though the grant was unconditional and I wasn't given any editorial direction or limitations. I was especially careful to make sure that no particular points of view were represented other than the prejudice that came from my own head—and that is I believe that people in pain need

I am an artist . . .

Hertz Nazaire (Naz)
Birth Place: Port-Au-Prince, Haiti
Birth Date: October 2nd, 1973

"I AM AN ARTIST..." You know, that really feels good to say, although my mother always wanted me to become a doctor, since I was always seeing one as a child. I live with pain and I've found much healing in art. I feel I can do more healing in this world as an artist than I could have ever done as a medical doctor. I find that my work can help others heal as much as it helps me with my struggles and pain. I'm mostly known around the world for my "Sickle Cell Series," which is made up of three paintings expressing living and coping with chronic pain.

One of Mr. Rosenfeld's subjects, a young artist named Hertz Nazaire, is twenty-eight years old, and suffers from sickle-cell anemia. Rosenfeld interviewed him in his apartment in Bridgeport, Connecticut. This is an excerpt from the interview.

Q. Do you think of yourself as a person in pain?

Nazaire: I think of myself as an artist. That's how I define myself. That's the thing that keeps me going.

Q. What is the source of your chronic pain?

Nazaire: Sickle-cell anemia. I was born with it. I've had it all my life.

Q. What is your first memory of pain?

Nazaire: I remember my mother rocking me back and forth to make me feel better when I was a baby. The subtle movement was like meditation. It had a calming effect on me. I was born in Haiti. There was no medication

to be treated.

Q. How did you go about finding people to interview?

Rosenfeld: I made the rounds of my personal contacts in a variety of fields. Sometimes one name would lead to another. Sometimes there was an obvious person who somebody knew was good. I think of one pain patient in particular. His name is James Hanlon. I was on a work/play trip to Hawaii giving some spiritually oriented seminars on the island of Maui, and through the course of the week, I met people involved in an organization called Arika. Through these contacts, I met an enormously talented artist—an AIDS patient who was in terrible pain.

I arranged to meet James, because I wanted to buy his artwork. I went to his very modest studio, which was covered with breathtaking artwork. Soon after meeting him, I knew I needed to get my tape recorder. I wasn't planning to do more interviews. I had enough, but it ended up being

one of the best pieces in the book. He was an enormously riveting character—fascinating to look at and listen to. I hung onto every word he said. His whole life was filled with pain that stemmed from a number of sources including his father's abuse, his experience working in an AIDS ward in San Francisco during the height of the AIDS epidemic, the horrible deaths of his lovers and his friends, and the physical pain he endures from his treatments and manifestations of the disease. All of that was tragic, but that didn't make him a good candidate for the book. It was his transcendent spirit.

In the healthcare area, one guy springs to mind: Gerald Young. I got him by reputation. He was the only practitioner in a rural area of Idaho—which was not a place I associated, through my own prejudice, with enlightened thinking about social causes. This was the only fellow who would provide pain relief—of whatever sort—for the needy, rural practice he conducted. His own disdain for members of his own profession, and his acceptance of the pariah role in

(continued on page 7)



available there, not even an aspirin, so I just had to deal with the pain I went through as a child. It was awful then and it is awful now. The difference is, now I manage my pain, but in Haiti things were really different.

Q. Is the pain throughout your body, or is it mostly in a particular place?

Nazaire: Sometimes in the joints, sometimes in the chest—anywhere that I have a blood vessel. If it happens to be in the brain, I get a stroke.

Q. What causes the pain?

Nazaire: A normal red blood cell is supposed to be round. Sickle-cell anemia changes it into a half-moon shape. My blood cells are no longer round and soft. They're sickle-shaped and hard, and they get stuck in veins. When they get stuck, the area gets blocked, the oxygen doesn't get to the tissue, the tissue starts to suffocate, and that causes pain. That's how it happens.

Q. How were you treated by friends and family when you complained of pain as a little boy?

Nazaire: I was treated as different. My mother was very overprotective. I wasn't supposed to join the Boy Scouts, although I did join them,

(continued on page 7)

Power Over Pain

Florida Nurses Lead Community-wide Pain Campaign

One morning about a year and a half ago, pain management nurse and president of the North Florida chapter of the American Society of Pain Management Nurses (ASPMN), Ellyn Radson, woke up with an idea she knew would work—a community-wide pain awareness campaign. Wasting no time, she organized her ASPMN chapter and other nurses in the community, brought the American Pain Foundation on board as the national partner, and looked for corporate underwriting.

According to Radson, "An estimated 50,000 residents in our community suffer with unrelieved pain, and pain almost always reduces productivity and destroys the person's quality of life. We know that people heal faster and stay healthier when their pain is controlled, but too often they suffer in silence or don't know where to turn for help."

Using APF's Stop Pain Now! Community Action Kit as a starting point, Radson and a steering committee of ten nurses created Power Over Pain. The goals of the campaign were to: provide people with information about the impact of untreated and under-treated pain on their health; let them know about their rights and responsibilities in relation to appropriate pain assessment and management; and educate people about effective ways to communicate pain to their healthcare professionals.

How was the name chosen? "Power Over Pain" was selected because it offered hope—hope that pain can be controlled," says Radson. "It also implied patient involvement, and the purpose of the campaign was to empower consumers to speak up when they experience pain."

Covered throughout by area newspapers, TV and radio stations, Power Over Pain was launched with Pain Awareness Week Proclamations by both the City of Gainesville and Alachua County. The week-long activities included: twelve presentations to a variety of audiences ranging from seniors to Rotary Club members; participation in two health fairs that drew over 250 people; and displays set up in all of the area's hospitals. APF and other materials were distributed widely at these events. The group also produced a large, attractive calendar with information about

Power Over Pain offered hope—hope that pain can be controlled.

where to go for help in the community as well as a list of national resources.

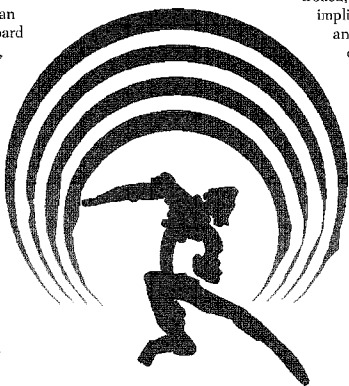
What was the key to success? Radson says there were several factors. "First, we involved key players from all major provider groups and facilities. And we got all the major medical institutions to include Power Over Pain in their advertisements."

"We also made sure to schedule the campaign at a time when it wouldn't compete with other major community events. And we found an excellent local advertising agency that worked for us at a very low cost."

"From the start, we involved the media, which resulted in two major feature stories in the *Gainesville Sun* and other coverage," Radson explains. "But key to the success of the program was hiring a part-time coordinator who knew how to manage a campaign and could take care of all the details. We were able to do this with a grant from Abbott Laboratories. Other pharmaceutical companies (Purdue Pharma, Ortho McNeil, and Janssen Pharmaceuticals) also provided underwriting for dinners and box lunches, which really helped attract a lot of people, and they gave us tons of non-branded patient materials for hand-outs."

Will they do it again? "Definitely. Next year we will plan a major newsworthy event so we will be able to get even better TV coverage. Also, we'll use the campaign as an opportunity to have our experts educate the local legislators, because pain issues are likely to surface in the coming legislative session."

For more information about how to get the Power Over Pain Community Action Kit, contact Lisa Nuth at 410-783-7292 ext 222, or write her at lnuth@painfoundation.org ■



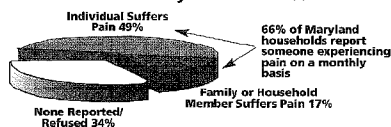
APF/MPI Survey Shows One in Three Marylanders Suffers with Serious Pain

One in three Marylanders said they suffer with moderate to severe pain—a condition that impacted almost every aspect of their lives including sleep, work, and social and sexual relations. These were some of the findings of Pain in Maryland, a recent survey of 625 Marylanders, conducted by Mason-Dixon Polling Research Inc. for the American Pain Foundation (APF) and the Maryland Pain Initiative (MPI). Other top-line findings included:

• Incidence and Frequency of Pain

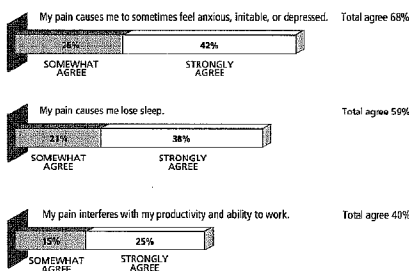
Approximately 1.4 million (66%) households in Maryland had at least one person suffering with pain. As many as 49% said they experienced pain on at least a monthly basis. Of these respondents, 40% experienced pain every day, or almost every day.

Incidence of Pain in Maryland Households



• Impact of Pain

Pain caused the majority of pain sufferers (68%) to feel anxious, irritable, or depressed. More than half of those with pain (59%) said their pain interfered with their ability to sleep. Forty percent said their pain interfered with their productivity and ability to work. Thirty-one percent said their pain interfered with their sexual relations, and 21% say it negatively affected relationships with friends and family. Twenty-five percent said their pain caused them to feel helpless and alone.



Sign Me Up!

Request a free copy of APF's new brochure, *Finding Help for Your Pain—A Pain Resource Guide*! Complete and return this form for your free copy. We'll also ensure you continue receiving *The Pain Community News* and our new e-newsletter, *APF Pain Monitor*. To sign up on-line, go to our website, www.painfoundation.org, and click on "Contact Us" and fill out the "Get Involved" form. In the comments area write "Send Finding Help for Your Pain." For larger quantities or reprint information, please fax or email your request.

- ☐ Send me a copy of *Finding Help for Your Pain—A Pain Resource Guide*.
☐ Enclosed is my contribution to APF.

Name _____

Address _____

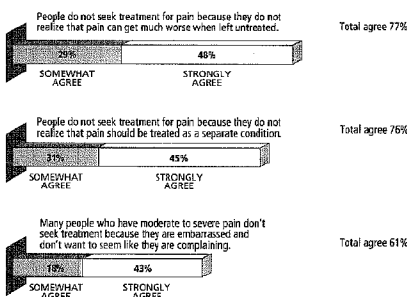
City _____ State _____ Zip _____

Email _____

American Pain Foundation
 201 N. Charles St., Suite 710
 Baltimore, MD 21201-4111
 Toll-free: 888-615-7246 (PAIN)
 Fax: 410-385-1832
 Email: info@painfoundation.org

• Attitudes Toward Pain

Over half the respondents (65%) said that pain is just something they have to live with or it is just a part of growing old. Sixty-one percent said that people don't seek help because they are embarrassed and don't want to seem like they are complaining. As many as 78% of regular pain sufferers said they have never been referred to a pain specialist.



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Hurting While Black

Racially Based Disparities in Pain Care by Richard Payne, M.D.



Richard Payne, M.D., Chief, Pain & Palliative Care Service Memorial Sloan-Kettering Cancer Center, New York, N.Y.

The Surgeon General's Healthy People Agenda lists the elimination of health disparities by the year 2010 as one of its key goals. Although the agenda emphasizes infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV infection/AIDS and immunizations, we also need to focus on another inequality that cuts across all diseases namely—racial and ethnically based disparities in pain management.

At least nine recent studies document racial and ethnically based disparities in access to pain medications and outcomes of pain treatment. Collectively, these depict a dis-

turbing situation that must be scrutinized by the public and professionals.

Race and ethnicity have been shown to play a role in pain management in almost every clinical setting—the doctor's office, emergency room, hospital, and even the community pharmacy. A particularly shocking series of studies reported that Hispanic and black patients were much more likely to receive no pain medications in the emergency room as compared with white patients, even when seen within six hours after suffering a leg fracture. This occurred even though patients in all racial groups reported equally strong pain and physicians assessed

pain as being equally severe in all groups.

Other studies have documented that the amount of pain medications prescribed to black, white, and Hispanic patients after surgery was influenced more by the race and ethnicity of the patient than by the intensity or site of pain.

Race and ethnically based inequities also exist in the outpatient assessment and management of pain. For example, findings from a series of studies conducted over the past six years by the Eastern Cooperative Oncology Group showed that more than one-third of

cancer patients received inadequate analgesics for cancer pain, and African Americans, Hispanics, and women are approximately three times more likely to be undertreated than white males. In addition, 65 percent of minority patients with cancer-related pain were undertreated according to the recommendations and standards of the World Health Organization and the Agency for Health Care Policy and Research, U.S. Department of Health and Human Services.

Recently, a suspected barrier to pain management for minority patients was documented. In a highly publicized study of a random sample of New York City pharmacies, 51 per-

Race and ethnicity play a role in pain management in almost every clinical setting—the doctor's office, emergency room, hospital, and even the community pharmacy.

cent of 347 pharmacies in minority communities areas did not stock sufficient opioids, which are essential for pain management in patients with severe pain. In contrast, 72 percent of pharmacies in neighborhoods with at least an 80 percent white population were found to have adequate opioid supplies. This difference occurred even though, according to police statistics, pharmacies in the minority and poor neighborhoods were no more likely to experience theft of controlled substances than pharmacies in more affluent communities. Patients with severe pain or dealing with terminal illness in minority com-

munities were able to obtain pain medications only after their families spent many hours searching from pharmacy to pharmacy.

Factors other than racial or ethnic characteristics might have accounted for some of these discrepancies. When the pain studies are taken as a whole and the facts are examined, however, there can be little doubt that race accounts for many of the disparities in both the prescription and availability of drugs.

To the extent that these disparities in pain care are often based on healthcare providers' assumptions about patients—seeing them through the "lens" of race—rather than on medical circumstances, the issue of "patient profiling" must be raised. The effects are just as pernicious, even if unintended, as racially based profiling by police who stop young black men driving expensive cars on the assumption that they are criminals. Is it possible that their "crime," known as "driving while black," has similar roots to the racial disparities in healthcare in general, and pain management in particular? ■

Did You Know That...

In the emergency room, Hispanics are twice as likely and blacks are two-thirds more likely than whites to receive no pain medications for fractures of the long bones. Blacks, Hispanics, and women have a threefold increased risk of undertreatment of cancer pain. When physicians program patient-controlled analgesia (PCA) pumps, the patient's race was a more important determinant of the amount of pain medication given than the intensity or site of pain or the type of surgery performed. In a survey of 347 pharmacies in New York City, 56 percent of the pharmacies with no supplies of opioids were in predominantly non-white neighborhoods.

National Medical Assn. Meeting Cites Poor Pain Management As Major Problem For Blacks

Excerpted from a September 2, 2002 article in Jet Magazine

Racial profiling by doctors and pharmacies, as well as the lack of black physicians, contribute to inadequate pain management, a serious national public health problem that affects millions of blacks and other underserved minority populations, according to an ongoing study by the National Medical Association (NMA).

During the convention the NMA convened a consensus panel to discuss the challenges of pain management as it relates to blacks and other minorities. Based on the NMA's preliminary study findings, racial profiling is more prevalent in pharmacies located in urban areas where pharmacies either refuse to carry certain opiate medications for fear of robbery, or a belief that prescriptions will be diverted for illegal use.

The organization suggested an integrated pain management curriculum be added to medical and related health education programs at the undergraduate, postgraduate, and continuing medical education levels.

The NMA, which represents the collective voice of 25,000 black physicians, continues to evaluate disparities in pain treatment based on race.

The Association plans to issue its final report on pain management in March 2003.

The National Medical Association is the nation's largest and most renowned scientific assembly on health issues affecting minorities. ■

Update! 2003 Study Finds Racial Discrepancies in Treatment of Chronic Pain

From study presented at the March 2003 American Pain Society's annual meeting

African Americans are less likely to receive adequate treatment for pain—from arthritis to backaches—than whites, according to two recent University of Michigan studies that were presented at the American Pain Society annual meeting, March 2003. In one study, 136 whites and 101 African Americans with chronic pain were surveyed. According to Dr. Carmen Green, lead researcher, "It seems there are differences in the area of referral." Green also said the African Americans believe their ethnicity affected their access to health management in general, and they believe their ethnicity affected their access to pain management. Findings also showed that doctors took longer to give African

Americans referrals to pain management centers than they did for whites. The study also suggests that many patients, particularly blacks, are not receiving proper pain treatment until their symptoms are so severe that their daily activities are affected. Additionally, findings indicated that doctors took longer to prescribe medications to African Americans than whites, and that African Americans on the whole have less access to medications even when they are covered by health insurance.

Findings of a related study of African American and white women with chronic pain showed that black women had greater levels of pain, depression, disability, and post-traumatic stress illness than white women. ■

Spotlight on the Intercultural Cancer Council

Diverse Membership Works Together To Bridge the Gap in Cancer Disparities

Racial and ethnic minorities and people with low-level incomes experience disproportionately greater suffering and death from cancer as compared with the U.S. population as a whole. To bridge this gap, the Surgeon General's Office vowed to eliminate—not reduce—these disparities as part of the Healthy People 2010 initiative. A monumental challenge? Perhaps. But one that the Intercultural Cancer Council (ICC), one of the nation's largest multi-ethnic and multi-disciplinary coalitions, is working to meet.

ICC was established in 1995 for the purpose of promoting policies, programs, partnerships, and research to eliminate the unequal burden of cancer among racial and ethnic minorities and the medically underserved in the United States and its territories.

"For these people, there's a higher incidence of preventable cancers, an excessive undertreatment for treatable side effects—including pain—a higher mortality rate for treatable or curable cancers, and a diminished period of survival," explains Susan Shinagawa, ICC's chair, cancer survivor, advocate and chronic pain sufferer.

In 1999, ICC became a nonprofit 501(c)(3) organization, and formed a 501(c)(4) arm for the purpose of legislative advocacy. Today, the coalition consists of more than 9,000 individual and organizational members in all 50 states, several U.S. territories, and including American Indian tribes and nations.

What are the reasons for undertreatment of cancer in minorities? According to ICC's *Problem Statement*, they include a lack of access to services, unavailability and underutilization of health services, poverty, lack of scientific research and information about minorities, and racial, institutional, and social injustice.

To bridge the gap in cancer disparities, ICC provides a forum to identify shared problems, develops collaborative solutions, and promotes new partnerships. Its primary educational activity is the *Biennial Symposium Series on Minorities, Medically Underserved & Cancer*. The largest gathering of its kind, the Symposium brings together health professionals, scientists, community-based organizations, policymakers, and interested individuals to address cancer disparities in terms of barriers and solutions. Symposium goals include: to exchange the latest scientific and treatment information; increase awareness and competence of healthcare providers, researchers and lay persons; and, promote culturally competent cancer care and services and ethnically balanced research, particularly

in clinical trials.

During Symposium off-years, ICC convenes the National Network Meeting, in which various communities explore potential collaborations and partnerships. Another of ICC's major activities is advocacy. When relevant legislation comes up in Congress, ICC puts its network into action.

ICC's was the driving force behind the congressionally mandated and funded Institute of Medicine landmark report, *The Unequal Burden of Cancer*. "The report brought awareness to the health world and the nation that disparities were not being addressed" says Pamela Jackson, ICC's director of Outreach Programs and ICC National Network.

Pain issues have been a major focus of ICC over the last year. At its Symposium this past February, ICC held a workshop on pain management co-chaired by Dr. Richard Payne, and incoming ICC Chair, Dr. Jim Hampton. In addition, the Symposium featured a morning session called *Pain Management, Special Consideration for Ethnic Minority and Medically Underserved Populations*. At its October Board meeting, ICC also invited special presentations on pain by APF and the American Alliance of Cancer Pain Initiatives.

To what does ICC attribute its accomplishments and success? According to Shinagawa, "We're accomplishing this through our diverse membership—men and women from throughout the country, scientists and researchers, clinicians and public health educators, leadership of nonprofit health agencies, medical associations, civil and human rights organizations, and cancer survivors—in every size, shape, and color of these United States.

"But our real strength and power," Shinagawa continues, "lies in the fact that, in spite of our differences and areas of focus, ICC members are committed to speaking with one voice. This is our motto, and it's the single most important ingredient to our success." ■



"'Speaking with one voice' is our motto and it's the single most important ingredient to our success," says ICC's chair, Susan Shinagawa.

Brown (from page 2)

physical medicine specialists, and others. Also, specialists and clinics range from those using one primary therapy (such as injections or physical rehabilitation) to a multi-disciplinary approach that combines therapies (physical rehab, psychological counseling, injection therapies, or medication management). These tend to be the most successful.

Try to find a specialist or clinic that will do a comprehensive review of your pain problem. Unfortunately, many of these services are still fragmented. Check with your provider and insurance carrier concerning pre-authorization, referral, and provider network requirements.

Gather your medical records and any diagnostic tests and send them to the provider prior to your visit.

Q. What questions should patients ask the provider?

Brown: It's a good idea to "interview" the physician. Ask questions such as: How long have you been practicing? Are

you certified in pain management? What hospital(s) are you affiliated with? Additional questions might include: How do you stay current in your field? Are you a member of the local hospice or the local medical or pain association? Do you have experience treating my type of pain? May I speak with any of your patients? Typically, people are not used to interviewing their doctors. But this kind of direct communication is all part of self-advocacy and taking control of your pain.

Q. What advice would you give to a person with pain living where there are no specialists?

Brown: This is a difficult problem. Begin by contacting the local hospital and asking them if they offer any type of pain services. If not, ask if there is a large hospital system in your area that offers outreach clinics or visiting physicians. Contact the Hospital Board of Directors or call your local Chamber of Commerce to find out where persistent pain is managed in your community. I also suggest alerting local legislators about the lack of

resources in the area and asking for assistance.

The bottom line is that there is a pain crisis in this country. Good pain care is difficult to access—whether you live in an urban or a rural area. Even those pain sufferers armed with the right information and willingness to advocate for themselves often find it hard to get help.

Unfortunately, too few healthcare professionals have been trained to manage pain. And many are fearful of prescribing strong medications. Insurance carriers have been known to not authorize particular types of pain treatments. The list goes on.

The good news is that there are a number of organizations and individuals working together to improve access to good pain management on several fronts—from legislative advocacy to public outreach.

But I truly believe that the greatest potential for reform lies with you, the consumer—the person with pain. The pursuit of options for pain relief needs to be just as unrelenting as the presence of persistent pain itself. Is anybody out there? Yes, we are! ■

Their Voice is Growing Louder and Stronger ICC 2003 Update

ICC and CIS Present Educational Forum in Puerto Rico

(August, 2003)
The Intercultural Cancer Council in partnership with the Cancer Information Service presented the first ever educational forum in Puerto Rico to discuss approaches to health disparities and cancer control. Entitled Comprehensive Cancer Control in Puerto Rico: Challenges and Opportunities, the two-day conference in San

Juan attracted over 130 scientists, healthcare professionals, academicians, survivors, and governmental agency representatives.

Attendees shared insights learned about cancer control issues facing residents of Puerto Rico, and presented alternatives for addressing the problems identified. The meeting focused on building partnerships among various organizations with the goal of increasing collaboration over the course of the next year.

State-by-state Initiative

ICC is presently discussing a partnership with the Centers for Disease Control and Prevention to develop a new regional initiative for the purpose of identifying and connecting community-based organizations with others in their areas (such as survivors support groups and hospital navigation services), and with resources. This initiative is a state-by-state effort to develop state cancer plans.

Physicians' Pocket Guide

Through a grant from the Health Resources and Services Administration, ICC is working on the Physicians' Pocket Guide. This ready reference will be small enough to fit in a physician's pocket and will have cultural information that is relevant to a patient's visit to a physician. This will allow physicians basic preparation before appointments and make them more responsive and sensitive to cultural differences.

Rosenfeld

(from page 3)

order to do what he felt morally obligated to do as a healer, was very impressive to me. Not that he does more important work than a top specialist in a top pain clinic who may see a lot more people and may wrestle with more technically difficult cases, but his humanity was incandescent.

In the last group, the thinkers, it was more difficult to pick somebody who sticks out. The issues, when it comes to doctor and patient, are more binary. *Hey, I'm a patient, help me, or, Hey, I've been trained to help. I should be helping.* Those are black and white things. In the third part of the book, where thinkers expound on chronic pain, they expound on things I didn't know about. Everyone had a unique take. For example, Rabbi Rami Shapiro, a wonderful writer, brought up the obvious story of Job. He also brought out things from his unique integration of East and West. Father Robert Kennedy, a Jesuit priest, discussed pain from a Christian perspective, which was new to me because I wasn't familiar with Christian orthodoxy.

If there's a theme in the book it may be slightly Buddhist, because Buddhism has more overt to say about human suffering than any other religion. There's a Buddhist contribution by Madeline Ko-I Bastis, who was the first Buddhist to be ordained as a hospi-

tal chaplain. She had certain ideas about suffering, pain management, and what it meant to be in pain, and what's the purpose—or not purpose of it.

Q. Did your personal biases shift after interviewing all those people?

Rosenfeld: The book does have definite biases. Those I freely give and admit to. I'm biased against a healthcare system that denies pain relief to people who are suffering; against a political and social environment that leads to people treating each other with dispassion; against a professional code that puts scientific inquiry above compassion and action; and, against a religious system that embraces a stiff upper lip as a precept.

I couldn't have gone forth with those biases and orchestrated the book that came out, because I couldn't know what people were going to say, and not everyone agrees. Sometimes representing a lack of awareness of the problem [pain] is a good way of illustrating the problem itself. And this existed in all three categories of interviews I did—people who weren't keenly tuned into it—and that was telling.

What changed in you while doing this project? And what have you learned?

Rosenfeld: I don't know if I can give a small answer to

such a huge question. The book represents an enormous amount of work. I think I matured a lot while doing that work—as writer, as a man, as a husband, as a father, as a thinker. It took two and a half years to travel around the country, transcribe and edit all the interviews, and then put them together in a cogent way. It was never easy. I wanted to move the project forward to completion, but

the revelations the process brought. I had to confront my own prejudices—I have a certain amount of stoicism in my character for instance, and it doesn't serve me well—and I was judgmental about certain things too, about doctors who go into medicine for the money or the status or the power and not out of a desire to heal, and also for those who choose to be

physicians out of scientific curiosity. I believe I was wrong in that last bias now. In my interview with Dr. Kathleen Foley I came to understand that while the need for compassion is over-arching and critical, competence is also key.

They are two wings of the same bird. Take away either, and doctoring doesn't work properly.

I also didn't realize the complexities and difficulties

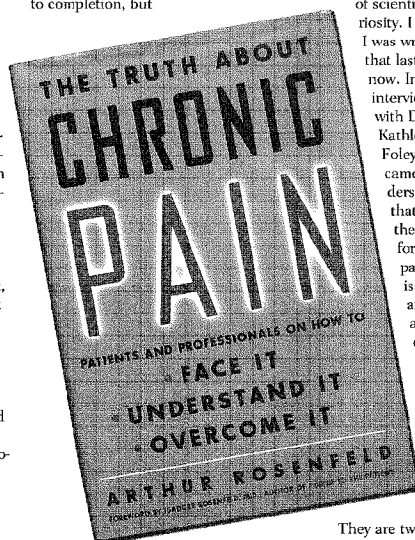
doctors face, nor how a doctor's empathy and ego can struggle in the face of intractable pain, in the face of a problem they cannot solve. Professional failure can lead to self-doubt in some doctors, and, in turn, to shunning the source of that self-doubt, the patient. Of course I also came to see that pain is a complex, multi-dimensional phenomenon, an expression of psychology, culture, anatomy, pharmacy, and most of all an expression of the individual.

Q. Were there any new breakthroughs in pain discussed?

Rosenfeld: What's breakthrough in this book is its candor—the willingness to say what most people shy away from and are afraid to say. I hope the work is a revelation of the process whereby doctors draw conclusions and make assumptions about patients, and patients do the same about doctors. I hope it is a revelation of the very personal nature of pain.

Q. Who will read this book?

Rosenfeld: I think the audience is very broad. Everyone, in some way, is touched by pain. ■



The Truth About Chronic Pain: Patients and Professionals on How to Face It, Understand It, Overcome It, published by Basic Books, is available at bookstores.

Nazaire

(from page 3)

but I wasn't allowed to go on field trips, which are really a big part of the scouts. I didn't play any sports. Mostly I hit the books and did my art. I've been painting since I was a little kid. It's been my best friend.

Q. How often do you go to the hospital?

Nazaire: It varies. Sometimes it's no more than twice a year, but there was a three-year period when I was in the hospital for ten months out of the year. Sometimes, I get sick but I take care of myself at home. Everyone at the hospital knows me, because I've been going to the same hospital since I was a child.

Q. How old were you when you came to the United States?

Nazaire: I was nine...My mother was here before I was. She was an immigrant in New York, and it would have been difficult to bring me along at the beginning because I was sick. The doctors always told her that I would die before I got to the age of eighteen. She left me in Haiti and came here searching for a dream, and when the dream happened, she sent for me. She died in a car accident when she was in her thirties and I was fourteen.

I was in the car. She was my safety, my comfort. That loss is an important part of my life. It's something that I have to live with.

Q. [Where did you go to] college?

Nazaire: I wanted to follow the arts thing. I made the mistake of going to the Art Institute of Fort Lauderdale. I wanted to get away from the winters, and I liked the colors down there in

Florida.

Q. Why was it a mistake?

Nazaire: ...Florida turned out to be a mistake because pain management in Florida seemed like the worst in the country. It was terrible. I was getting sick left and right because they didn't manage my pain...But having a chronic illness, you really need your doctor to back you up...I was in the intensive care unit many

times with acute-chest syndrome—pain that could kill me.

Q. What is acute-chest syndrome?

Nazaire: Sickle-cell damages organs because you're sick all the time. When you get pneumonia a lot and the lungs collapse and there are complications, that's acute-chest syndrome. That happened to me many times, but I survived it. Twice, I survived my heart stopping. There are so many things that happen with sickle-cell that I can't think about next week because although I'm sitting here today, I'm not sure when I'll get sick. I could get sick tonight. I could get sick two hours from now, or I could get sick next week. It's very hard to plan what you have going on. The pain is very strong, and you can't do anything when you're in crisis. ...You can't really function when you're suffering like that. ...Letting people inside, trusting them, that's hard for me. I had trouble trusting doctors for a while. For a long while, I didn't trust them at all.

Q. Did you think they had some agenda other than to help you?

Nazaire: In pediatrics, when I was a child, everything was great. The nurses cared; there was a toy room; there were all these doctors hovering over me

all the time. People don't want to see a child in pain. But as soon as I turned eighteen, became an adolescent, moved on to a regular hospital floor, things changed. People treated me differently.

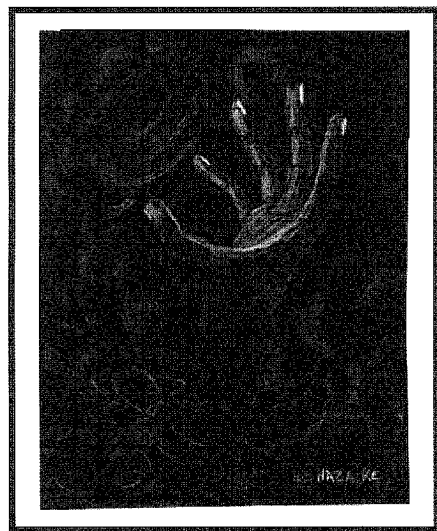
Q. They regarded your pain differently?

Nazaire: They regarded me as a person differently. It felt as soon as I stepped into the emergency room that judgment was passed against me. There's a stigma attached to sickle-cell patients. It's like they thought I was seeking drugs. They didn't believe I was in pain.

Q. Do you have friends now on whom you can rely?

Nazaire: I have relationships with the local sickle-cell organization. I volunteer through them, do health fairs, try and help other people that have sickle-cell like me. That group is my support structure...The most important thing for me is to get a positive message out to people out there, kids growing up with this feeling of hopelessness, people who are not being treated well by their family and are afraid of what is happening to them, afraid they might die...

People have to know that they can survive this. More than survive. They can get it all, everything that they want and desire. It's very important that they know that. ■



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Addiction, Physical Dependence, Tolerance. Confused?

(from page 1)

with pseudoaddiction—which is mostly what we see,” said Dr. Ray. “These distinctions are particularly important for family practitioners who deal with these issues everyday.”

Physical Dependence and Tolerance

Physical dependence and tolerance are also often con-

the same rate for all of the effects of the drug. For example, a patient will develop tolerance to sleepiness and respiratory depression [trouble breathing] very quickly, but not to constipation or the analgesic effects. Many people can take high doses [of opioids] with no mental impairment and retain good analgesia. But this is not true of everyone. It takes about a

Addiction, Physical Dependence, and Tolerance Defined

Addiction is a primary, chronic, neurobiologic disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations. It is characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving.

Physical Dependence is a state of adaptation that is manifested by a drug class specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist.

Tolerance is a state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug's effects over time.

fused with addiction. But, according to the consensus paper, both of these are normal responses to regular use of some prescribed medications (including opioids), and are not evidence of an addictive disorder.

Physical dependence refers to the fact that when some drugs are stopped or the blood level of the drug is decreased, withdrawal symptoms emerge. Withdrawal symptoms can occur from a number of drugs (e.g., beta blockers and antidepressants as well as opioids). The paper cautions that the term detoxification should not be used when a medication is being stopped or tapered off.

Tolerance develops when the effects of a drug diminish with exposure, or when greater doses are needed to produce the same effect. “The body is designed to develop tolerance to almost anything it's exposed to. It's a compensatory response,” said Dr. Covington. “Patients develop tolerance to all kinds of drugs that are in no way habit forming.”

“In terms of opioids, tolerance doesn't develop at

six-month trial with the drug to determine the assets and liabilities for the patient.”

Need for Universal Agreement Terms

“Our next step is to get buy-in on the definitions from various organization with influence in our arena, such as the American Psychiatric Association and the WHO, as well as federal regulatory agencies and medical boards,” Dr. Covington said. “Once we get agreement on definitions, we hope to develop some sensible, evidence-based policy recommendations for patients who have co-morbid pain and addictive disorders. It will help us manage patients with ‘double trouble.’”

The ultimate goal of the three organizations, according to the consensus statement, is “...to promote better care of patients with pain and other conditions where the use of dependence-producing drugs is appropriate, and to encourage appropriate regulatory policies and enforcement strategies.” ■

Vargas

(from page 2)

very against it. He was afraid that they would change my personality. He already felt that he had, in a sense, lost me after the accident. He was also afraid that I would become addicted.

When I started taking the medications, he still wasn't comfortable, but I was starting to feel better. They helped reduce the pain a lot and I never felt “high.” I wouldn't do anything that would alter my state of mind.

Q. Did you get complete relief?

Vargas: No. I had some relief but still felt sick. That summer, I went to New York to a pain program. The doctor began to suspect that the most serious injury was in the sub-occipital region and suggested I go to Johns Hopkins.

Again, my husband and I decided to take action and become educated consumers. After graduating from law school, I got a fellowship to work at the National Association of the Deaf Law Center in Silver Spring. I stayed with Dr. Gervin, but also went to Johns Hopkins, where I saw a series of doctors and

Q. How do you feel today?

Vargas: Now, with the stimulator and opioid medications, I'm finally feeling better. I'm not perfect, but my husband and I have started having fun again. We're making plans to travel, go camping, and walking. And he has changed his mind completely about medications because he has me back again.

Q. What advice would you give others in pain?

Vargas: I would tell them to trust their own opinions. There's no manual for finding and getting treatment, so you have to do a lot of research. Also, you need to be persistent and ask doctors hard questions. When they say you'll never get better—refuse to accept it! ■

Resource List**These resources are from our Finding Help For Your Pain: A Pain Resource Guide:****Find a Healthcare Provider**

- American Academy of Family Physicians
www.familydoctor.org
- American Academy of Nurse Practitioners
www.aanp.org 202-966-6414
- American Academy of Physician Assistants
www.aapa.org 703-836-2272
- American Board of Medical Specialties
www.abms.org 847-491-9091
- American Medical Association
www.ama-assn.org 312-464-5000
- Cancer Care
www.cancercare.org 800-813-4673
- Center For Patient Advocacy
www.patientadvocacy.org 703-748-0400
- Doctor Directory
www.doctordirectory.com 828-255-0012
- Federation of State Medical Boards (disciplinary history of physicians)
www.docinfo.org
- Federation of State Medical Boards (verify physician credentials)
www.fsmb.org 817-571-2949
- National Conference of Gerontological Nurse Practitioners
www.ncgnp.org 703-802-0088
- Nurse Practitioner Central
www.nurse.net/np 202-659-2190
- Yellow Pages
www.yellowpages.com

Find a Pain Specialist

- American Alliance of Cancer Pain Initiatives (find listings of state initiatives)
www.aacpi.org 608-265-4013
- American Academy of Pain Medicine
www.painmed.org 847-375-4731
- American Academy of Pain Management
www.aapainmanage.org 209-533-9744
- American Board of Pain Medicine
www.abpm.org 847-375-4726
- American Chronic Pain Association
www.theacpa.org 800-533-3231
- American Pain Society
www.ampainsoc.org 847-375-4715
- Cancer Care
www.cancercare.org 800-813-4673
- Case Management Resource Guide
www.cmrg.com 800-784-2332
- Commission on Accreditation of Rehabilitation Facilities
www.carf.org 520-325-1044
- Mayo Clinic Pain Management Center
www.mayoclinic.com/findinformation/conditioncenters
- National Hospice and Palliative Care Organization
www.nhpco.org 703-837-1500
- Pain.com
www.pain.com/painclinics/default.cfm

Reading
This
Could
Help EASE
YOUR
PAIN

PAIN ACTION GUIDE
AMERICAN PAIN FOUNDATION

**APF's New, Revised Pain Action Guide Is Here!**

The new PAG has more information for people with pain. A new section on treatment options explains how different types of pain can be treated and can act as a guide to the treatment option that is appropriate for you. This easy-to-read pamphlet helps people get answers to some of their most immediate questions, such as: What are my rights as a person with pain? How do I talk to my healthcare provider about my pain? How should my pain be treated? The new *Pain Action Guide* starts with the Pain Care Bill of Rights and helps readers take control of their pain. Included is a list of resources for taking action.

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